



UDOH & Health Research Admin Rules Committee

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MISSION & VISION



The Utah Department of Health's mission is to protect the public's health through preventing avoidable illness, injury, disability, and premature death; assuring access to affordable, quality health care; and promoting healthy lifestyles.

Our vision is for Utah to be a place where *all* people can enjoy the best health possible, where *all* can live and thrive in healthy and safe communities.



UDOH Responsibilities



U.C.A. 26-1-30

- (3) promote and protect the health and wellness of the people within the state;
- (5) investigate and control the causes of epidemic, infectious, communicable, and other diseases affecting the public health;
- (7) collect and report information on **causes** of injury, sickness, death, and disability and the **risk factors** that contribute to the causes of injury, sickness, death, and disability within the state;
- (8) collect, prepare, publish, and disseminate information to inform the public concerning the health and wellness of the population, specific **hazards**, and risks that may affect the health and wellness of the population and specific **activities** which may promote and protect the health and wellness of the population;

History



- 7/14/1982- Gov. Matheson established the Utah Resource for Genetic and Epidemiologic Research(RGE) as a data resource for the collection, storage, study and dissemination of medical and related information to be used for the purpose of reducing morbidity or mortality, or for the purpose of evaluating and improving the quality of hospital and medical care (UCA, 1953, 26-25-1, et seq.)
- 2/20/1986- Gov. Bangerter executive order to move RGE to the University of Utah (1982 order was not rescinded).
- 2/15/2016 - Executive order rescinded 1982 order and kept 1986 order.

What we share



- Only data where governing statute authorizes sharing for research purposes
 - Utah Cancer Registry (UCA § 26-3-7)
 - Vital Records (UCA § 26-2-22)
 - Health Facility and Claims data (UCA § 26-33a-109)
 - Autism Registry (UCA § 26-3-7)
 - Birth Defects (UCA § 26-3-7)
 - Parkinsons Registry (UCA § 26-3-7)
- Not all elements are shared
- Do not share where not allowed in statute (e.g. Communicable Disease governed by UCA § 26-6-27)

Agreements



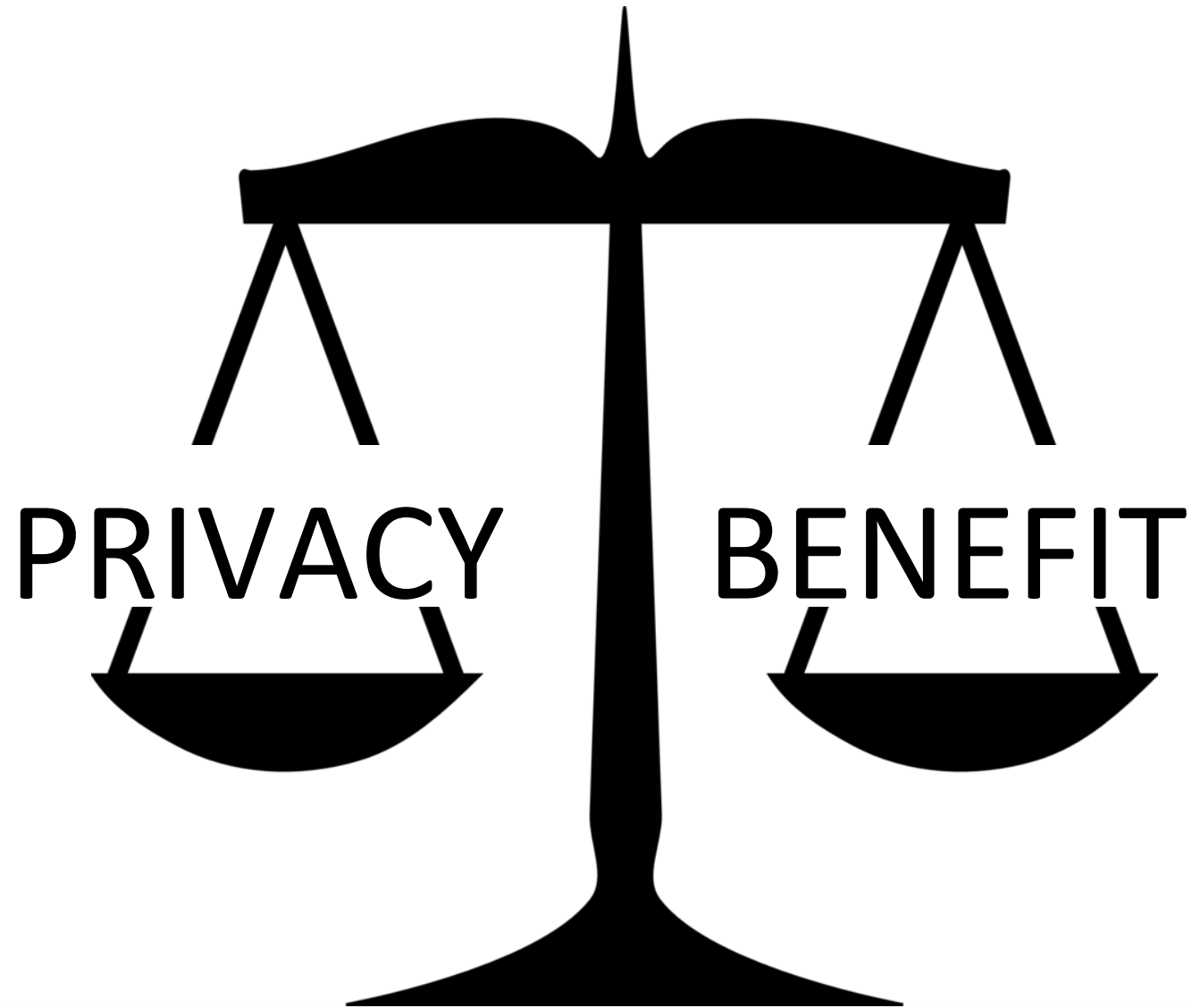
- Master agreement that covers privacy and security terms and conditions
- RGE agreement that covers oversight and responsibility related to RGE
- Individual dataset agreements that outline conditions not covered in the first two agreements.

Oversight Process



- Researchers must submit proposal to RGE
- RGE board includes representatives from data contributors
- Researchers must justify need for data elements they are requesting
- Board follows a minimum necessary policy
- Data contributors can veto
- Researchers must also seek Institutional Review Board review
 - Reviews ethics related to human subjects research and questions regarding informed consent
- Some Opt Out provisions

Balance



Security Benefits



- Central Repository for data from different systems
- Linkage in a secure location - fewer data transfers of sensitive information.
- Allows for release of minimum necessary
- Access to analyze in virtual environment rather than storage on individual researcher computers.

Other Benefits



- Utah Specific Data
- Linkages with other datasets
- Family history information
- Longitudinal information

Examples



- 1994 <https://pubmed.ncbi.nlm.nih.gov/7545954/> BRCA discovery – changed the standard of care and prevention for screening for breast and ovarian cancer risk
- 2008 <https://pubmed.ncbi.nlm.nih.gov/18063416/> A genetic change in the APC gene leading to precancerous polyps in the intestines and a 69% risk of developing colorectal cancer was identified in a Utah family dating back to the Pioneer emigration. Now with over 13,000 descendants, we have prevented colorectal cancer in 100's of individuals.
- 2019 [Risk for Alzheimer Disease Affected by Complete Family History](#) Scientists showed how a family history of Alzheimer's disease affects someone's personal risk. They recommend health care providers review family histories of both close and distant relatives when counseling patients about their risk of Alzheimer's disease
- 2018 [Increased Respiratory Medical Care in Children, Adolescents, and Young Adult Cancer Survivors](#) This study finds that children, teens, and young adults with cancer face severe respiratory illness from treatment for their cancers and require more health care. This study suggests interventions to reduce the health burden on younger cancer survivors.
- 2019 [Suicide Risk among Persons with Autism Spectrum Disorder \(ASD\)](#) Risk of suicide for persons with ASD grew over time and was greater than those without ASD, especially for females. This study points to the need for additional research in ASD related to suicide attempts.

Summary



- Share as allowed by legislature
- Focus on maximizing security and privacy,
- while also allowing use to inform research that may benefit the population